Personal dignity in seriously ill patients

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TOWARD AN IMPROVED CONCEPT OF PERSONAL DIGNITY IN THE QUALITY OF LIFE RESEARCH FIELD

ABSTRACT

It has recently been argued that the concept of dignity should be considered as an integral aspect of the quality of life and should be included as a domain in quality of life measurement instruments for long-term care. However, the research field pertaining to personal dignity has indicated that dignity is a complex and multi-facetted concept, influenced by both internal and external factors, making its measurement far from straightforward. This paper discusses some of the conceptual issues with regard to quality of life and dignity, and presents some key findings from the field of dignity studies, arguing that dignity involves more than respectful treatment. We hereby aim to further inform the quality of life research field on how personal dignity can be assessed in a meaningful manner.

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INTRODUCTION

In the quality of life discourse, some have recently argued that the concept of dignity should be included as an integral aspect of the quality of life (Manthorpe et al., 2010; Netten et al., 2012). Maintaining the dignity of individuals receiving care is increasingly considered to be a key care outcome within the context of quality of life research (Venturato, 2010; Forder & Caiels, 2011), and disregard for the individual's personal sense of dignity is believed to result in the deterioration of the health and quality of life of those who require care (Mann et al., 1999). As such, dignity is included as a domain in quality of life instruments that aim to assess the effects of long-term care on the quality of life of the care recipients (Kane et al., 2003; Netten et al., 2012). Dignity is a complex concept and its meaning and definition are often elusive. Modern philosophical reflection on the meaning of dignity in present-day society has resulted in various taxonomies of dignity (e.g. Nordenfelt, 2004; Jacobson, 2009; Leget, 2013). When discussing dignity in the context of healthcare, what is often referred to is personal dignity, a type of dignity that is subjectively felt and related to the individual's sense of worthiness (Chochinov et al., 2002a; Pullman 2004). Personal dignity is contingent and contextual, i.e. it can be affected and altered by one's perceptions of oneself and by the perceptions of and treatment by others. Empirical research on personal dignity in different health contexts has shown that personal dignity is influenced by multiple factors in individual and social domains, with the weight of each factor depending on contextual circumstances and differing between individuals (Chochinov et al., 2002b, and 2008; Jacelon et al., 2004; Hall et al., 2005; Jacobson, 2007; Slettebø et al., 2009, Lohne et al., 2010; Van Gennip et al., 2013; Oosterveld-Vlug et al., 2014a). Because personal dignity is a rich, multifaceted phenomenon, its measurement is far from being straightforward.

While the quality of life research field has embraced personal dignity as an important concept within the quality of life framework, limited attention has been given to the already substantial body of research carried out on personal dignity. As a result, in the measurement of personal dignity within the quality of life framework, the complexity of the concept is sometimes ignored in favor of a simple, one-dimensional definition of dignity which may miss essential elements. In healthcare and social policy making, quality of life instruments are frequently deployed to evaluate and improve care (Kane et al., 2003). In this paper we argue that when aiming to evaluate and improve care, it is essential to assess the personal dignity of those receiving care in an adequate fashion, doing justice to the multiple aspects relevant to personal dignity.

While quality of life and dignity are often mentioned in conjunction with each other when referring to individuals' well-being, the relationship between the two concepts is far from clear and has rarely been subject of theoretical scrutiny. This paper therefore

begins with an exploration of quality of life and personal dignity on a conceptual level, outlining what the concepts entail and how they may relate to or differ from each other. Subsequently, we present a selection of key findings from empirical research on personal dignity to further inform the quality of life field. We then discuss the assessment of dignity on a practical level by evaluating two well-established quality of life instruments that include a dignity domain (the self-reported QOL (Kane et al., 2003) and the ASCOT (Netten et al., 2012)). Finally, we provide further recommendations on how to assess personal dignity.

THE CONCEPTS OF QUALITY OF LIFE AND PERSONAL DIGNITY

The World Health Organization describes quality of life as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, affected in a complex way by a person's physical health, psychological state, personal beliefs, social relationships and their relationship to their environment" (WHO, 1995). This definition includes what philosopher Dan Brock has termed theories of preference satisfaction (the degree to which life fits the individual's preferences) combined with normative theories (the degree to which life fits current values and ideals) (Brock, 1989).

Another principle by which to assess quality of life is the hedonistic perspective, i.e. the degree to which the individual derives pleasure and satisfaction from life. A number of philosophers reflecting on quality of life regard happiness or satisfaction as an essential component (Brock, 1989; Veenhoven, 2002; Nordenfelt, 2009). Some philosophers and researchers take an entirely subjective approach to quality of life, stating that quality of life is equivalent to happiness with life (e.g. Nordenfelt, 2009). Others argue that while happiness is part of the concept, quality of life must also be determined by objective standards such as utility of life (Veenhoven, 2002) or cultural norms regarding what can reasonably be expected from life (Brock, 1989).

Health is often considered to be a main contributor to quality of life (Degenholtz et al., 2008; Nordenfelt, 2009). Well-functioning organs, the ability to move and the ability to reason and communicate, for example, are considered to be prerequisites for living a relatively full life (Brock, 1989). Characteristics such as these and the absence of the symptoms of illness can be measured objectively. On the other hand, the individual's perception of his or her level of health and whether or not subjective goals and desires can be fulfilled as a result are also relevant. Quality of life is thus comprised of both normative objective and normative subjective components.

Dignity (*dignitas, Latin*) refers to the worthiness of human beings. In contemporary thinking, a basic distinction is made between "human" and "personal" dignity. *Human* dignity is a moral and legal concept and refers both to an intrinsic, inalienable quality recognized for every human being by virtue of their humanity; i.e. every human being is endowed with dignity (Spiegelberg, 1970; Kant, 1981), and the right to be treated with dignity, which serves as the basis for human rights (Spiegelberg, 1970; Malvestiti, 2012).

When discussing dignity in the context of healthcare, what is most commonly referred to is *personal* dignity. This type of dignity is subjectively experienced and relates to the individual's sense of worthiness. Personal dignity is a matter of degree and can be gained or lost as the result of certain experiences or the acts of others (Chochinov et al., 2002a; Pullman, 2004). While quality of life focuses on the evaluation of life, the emphasis in personal dignity is on the self. Quality of life is concerned with the fulfillment of needs and goals and the appraisal of life, personal dignity relates to how the individual feels about him or herself, based on internal and external experiences. Disease or aging experiences can challenge the individual's sense of personal dignity because alterations to body or mind, limitations in ability and dependency on others can have a bearing on one's perceived sense of self and threaten to one's identity (Jacobson, 2009). Additionally, personal dignity is affected by the individual's understanding of how others perceive them. In order for the individual to feel dignified, he or she must feel valued by others. Conversely, feelings of self-worth can be adversely affected by the acts of others (verbal, nonverbal or behavioral) (Gallagher et al., 2008). Personal dignity is thus determined both by the inner evaluation individuals make of themselves (internal component), and by the acts and attitudes of others as perceived by the individual (external component). Because personal dignity is grounded in the evaluation of oneself in close relation to others, it is a more relational construct than quality of life.

Some philosophers argue that quality of life is primarily based on a cognitively guided evaluation of whether certain primary goals and expectations have been met, resulting in overall (dis)satisfaction with life (Brock, 1989; Nordenfelt, 2009). Dignity, as it relates to the individual's core being, has a strong emotional component. The positive presence of dignity is not always felt, but threats to dignity can instantly provoke powerful emotions such as anxiety, humiliation, embarrassment, sadness, and frustration (Hack et al., 2004; Franklin et al, 2006). Overall loss of a sense of dignity can result in the feeling that life is no longer worth living (Chochinov et al., 2002b; Jansen-van der Weide, 2005).

Quality of life and sense of personal dignity are interrelated; certain aspects of one's daily reality, e.g. having a sense of purpose in life, influence both the quality of life one experiences and one's sense of dignity. However, each concept refers to a different existential level and has a different outcome, i.e. being happy or satisfied with one's life and feeling like a worthy individual. While personal dignity relates to inner characteristics

and identity, to who one is regardless of circumstances, quality of life refers to actions and the potential to realize life goals. One can still have dignity with a low quality of life, i.e. one can be severely limited in executing daily activities and still feel like a worthy individual. However, the reverse - to experience a high quality of life, defined as leading a fulfilling life, without feeling dignified - appears to be a less likely scenario.

FACTORS AFFECTING PERSONAL DIGNITY

The growing body of empirical research on personal dignity has given the concept of dignity a firm practical basis by taking into account the everyday experiences of patients and healthcare professionals. Qualitative research has investigated how dignity is understood by patients and which components they find essential to their dignity. These studies have identified several factors central to a sense of dignity in the terminally ill (Chochinov et al., 2002a), in patients with serious chronic illnesses (Söderberg et al., 1999; Slettebø et al., 2009; Van Gennip et al., 2013), in patients with dementia (Heggestad et al., 2013; Tranvåg et al., 2014; Van Gennip et al., 2014), in nursing home residents (Hall et al., 2005; Franklin et al., 2006; Pleschberger, 2007; Oosterveld-Vlug et al., 2014a) and in patients receiving care in hospitals (Baillie, 2009). Various models illustrating the relationships between these factors have been developed (Errasti-Ibarrondo et al., 2014). What these models have in common is that they draw a distinction between social domains and individual domains. Which experiences affect the individual's sense of personal dignity, either enhancing or diminishing it, differs between individuals and is dependent on contextual circumstances (Van Gennip et al., 2013; Oosterveld-Vlug et al., 2014a). Some of the key factors identified in empirical research which can affect personal dignity in individuals needing long-term care, are:

- Life has meaning and purpose (being able to carry out normal routines, being of worth to and valued by family and friends, being able to contribute and reciprocate within relationships).
- Having control over one's own life (making decisions about what to wear and what to eat, having one's wishes taken into account, being kept informed, being taken seriously, being able to maintain individual routines at own pace).
- Aesthetics (maintaining personal cleanliness, being well-groomed).
- Privacy (respect for personal space, modest bodily care (e.g. not being exposed, normalized incontinence)).
- Recognition of individualism, acknowledgement of unique identity (life story is listened to, taking part in conversations).

- Being treated with respect and understanding by others.

Care aimed at maintaining dignity should promote a sense of meaning or purpose, as a way of staving off feelings of being a burden to others and no longer worthy of respect (Chochinov et al., 2008). Important to a sense of purpose in life is to be of meaning and value to others, and to be able to participate and reciprocate in social relationships. Baillie (2009) found that for patients in a hospital setting, dignity was enhanced by contact with fellow patients in similar circumstances, and by the establishment and maintenance of good relationships with hospital staff. Remarkably, the staff was largely unaware of the beneficial effects of these relational factors and focused primarily on privacy issues. Thus, it is essential that care aimed at maintaining dignity promotes social interaction. Additionally, care should facilitate the autonomy and sense of control of individuals who are care dependent as far as possible. A phenomenological study revealing patients' and nurses' perceptions of dignity carried out by Walsh and Kowanko (2002) found that patients felt their sense of dignity was maintained when they were given choices and had control over certain aspects of their care. Qualitative research further indicates that preserving the individual's identity is elementary to a sense of dignity (Van Gennip et al., 2013, and 2014). In long-term care facilities, this can mean that the patient is largely in control of his or her own life within the confines of the structure and regulations of the facility, and that he or she continues to have a purpose in life.

DEFINITION AND OPERATIONALIZATION OF THE CONCEPT OF DIGNITY IN THE QUALITY OF LIFE FRAMEWORK

In order to illustrate how the concept of dignity is currently measured within the quality of life framework, two well-established instruments that include a dignity domain and are frequently used to measure quality of life will be reviewed: the self-reported QOL (Kane, 2003) aimed at assessing the quality of life among nursing home residents, and the Adult Social Care Outcomes Toolkit (ASCOT) (Netten, 2012), which aims to assess the effect of social care services (delivered through personal assistance, nursing and residential care homes, and day centers) on the quality of life of the care recipients.

The self-reported QOL divides quality of life into eleven domains for assessment. The "dignity" domain consists of five items to be rated by nursing home residents on a 4-point scale (1=never; 4=often): 1. staff treats you politely. 2. staff treats you with respect. 3. staff handles you gently. 4. staff respects your modesty. 5. staff takes time to listen to you. A sum score is calculated, ranging from 5 to 20, whereby a higher score is more

positive. Additionally, a summary question assesses whether residents feel their dignity is respected.

A more recently developed questionnaire for assessing the quality of life of those receiving long-term care was designed by Netten and colleagues (Malley et al, 2012; Netten et al., 2012). This questionnaire, the ASCOT, discerns nine domains. The "dignity and respect" domain in this instrument covers two items: how the way in which long-term care recipients are helped and treated affects how they think and feel about themselves, and how being care-dependent affects how they think and feel about themselves, varying from positive (makes me feel better) to negative (undermines the way I think and feel about myself). Although the ASCOT does measure how treatment by caregivers affects the way individuals think and feel about themselves, the relationship between these feelings and the care recipient's sense of dignity remains unclear.

Both quality of life instruments assess dignity solely by measuring staff behaviour and attitude as judged by care recipients. This narrow conceptualization of dignity describes dignity as something that is bestowed by others. Yet research has shown that personal dignity is determined by multiple factors and experiences affecting how individuals value themselves, treatment by others being only one among them. Therefore, while disrespectful treatment by care staff can undermine the care recipient's sense of dignity, respectful treatment in and of itself is insufficient to maintain dignity. In order to safeguard dignity, it is essential that conditions are created that enable the patient's personhood to be respected and maintained, and that encourage the facilitation and promotion of autonomy, choice, reciprocal relationships, and a sense of purpose and meaning. Thus, in order to provide care that fosters the patient's sense of dignity, the way in which care is organized at the institutional level is just as important as positive staff attitude and behavior.

Quality of life measuring instruments are frequently used to assess the need for healthcare, the effectiveness of interventions, economic efficiency and the quality of a service (Schölzel-Dorenbos et al., 2007; Venturato, 2010). Measurements are also used for policy making, regulation, quality improvement and public information (Kane et al., 2003). It is increasingly recognized that maintaining personal dignity in those dependent on care should be a central aim of care, and dignity is increasingly considered to be a key outcome in quality of care. This realization has led to the adoption of the concept of dignity in quality of life measurements. Again, it is important to realize that a respectful attitude on the part of staff, in and of itself, is insufficient for maintaining the care recipient's sense of dignity. While these instruments claim to measure dignity, the definition of "dignity" used is inadequate and can lead to flawed assessments and recommendations. Reducing dignity to a one-dimensional concept fails to account for its complexity and in doing so has far-reaching consequences for the field of practical healthcare. Personal dignity needs to be

defined in a broader and more inclusive way, one which incorporates the many factors that play a role in determining the individual's sense of dignity.

ASSESSING DIGNITY

Dignity affects quality of life, and can even be considered to be a prerequisite for a good life. Therefore it is a valuable domain to be added to instruments assessing quality of life. It should be recognized, however, that dignity is a multi-leveled construct, and thus should be measured by multiple items that reflect its full meaning. This paper has referred to relevant literature and has provided suggestions with regard to the aspects and experiences that can influence the sense of personal dignity among individuals who are care dependent. If personal dignity is to be assessed by means of quality of life instruments, more items need to be included in the domain. Both qualitative and quantitative studies have shown that dignity is related to identity, and in order to maintain dignity central elements of the individual's identity need to be preserved. Research on dignity indicates that in order to maintain personal dignity and a sense of self when care-dependent, it is important to have a purpose in life, to be engaged in meaningful activities, to be of value to others, and to be able to exercise self-determination and be in control to some extent. Descriptions of dignity as an aspect of quality of life should be modified to include these elements at minimum.

Depending on the goals and the context of the quality of life study, it may be useful in some cases to measure personal dignity separately by making use of existing dignity instruments developed to assess dignity in care recipients. This approach can provide a more detailed account of how different factors, both external and internal, impinge on the individual's sense of dignity. There are a number of tools suited to different settings: the Measurement Instrument for Dignity AMsterdam (MIDAM), the Measurement Instrument for Dignity AMsterdam Long-term Care (MIDAM-LTC), and the Personal Dignity Inventory (PDI). These instruments are grounded in empirical, qualitative research. The PDI was developed by Chochinov and colleagues (Chochinov et al., 2008), and is suitable for assessing the sense of personal dignity in patients receiving palliative care. It consists of 25 self-reported items rated on a 5-point scale. Patients are asked to rate the degree to which each of the specific items or issues poses a problem for their sense of dignity (1=*not a problem*; 5= *an overwhelming problem*). The instrument consists of 5 factors (symptom distress, existential distress, dependency, peace of mind and social support) and lists experiences such as: "feeling that how I look to others has changed significantly"; "not being able to think clearly"; "not being able to continue my usual routines"; and, "feeling that I have no control over my life".

The MIDAM was developed by Oosterveld-Vlug and colleagues (Oosterveld-Vlug et al., 2011). This instrument is used in assessing individuals in poor health with severe impairments and combines both individual and care aspects. It consists of 26 items (symptoms and experiences) spread over four domains: (1) evaluation of the self in relation to others (e.g. feeling worthless to friends and family); (2) functional status (e.g. incontinence); (3) mental state (e.g. unable to make decisions); and (4) care and situational aspects (e.g. receiving insufficient attention for my wishes from doctors). For each item, respondents are first asked to indicate whether the item applies to them (yes/no). If the answer is affirmative, respondents are asked to further rate the extent to which this influences their sense of dignity on a 5-point scale (1=not at all; 5= very much). In addition, a single overall score for dignity is rated on a 10-point scale.

This instrument was further developed to specifically address personal dignity in individuals living in long-term care facilities, the MIDAM-LTC (Oosterveld-Vlug et al., 2014b). Items specific to long-term care facilities were added to the MIDAM (e.g. "difficulties with adjusting to the nursing home"; "feeling bored and experiencing every day as the same"; and, "feeling guilty about calling for the nurses too frequently"), resulting in a total of 31 items for the MIDAM-LTC. The instrument follows the same structure as the MIDAM.

The instruments described above have demonstrated excellent content validity and provide solid, reliable, full-range insight into dignity (Chochinov et al., 2008; Oosterveld-Vlug et al., 2011 and 2014b). Dignity instruments such as these enable a thorough investigation of the subject matter.

Yet another approach toward gaining a better understanding of personal dignity is interviewing individuals receiving care. Face-to-face interviews provide an in-depth and highly personal view that can add a new and valuable dimension to the understanding of dignity in actual practice. Research has indicated that although there is general agreement about the types of components that constitute dignity, there are also individual differences, and the extent to which each property of dignity is prioritized differs per individual (Clark, 2010). When customizing care for individual patients, caregivers should consult with the care recipient regarding the type of care they require in order to maintain their sense of dignity. Additionally, holding conversations with care recipients can improve the insight of staff and caregivers into the kind of care necessary for maintaining dignity and can be a useful starting point for further developing dignity-sustaining care, thus enhancing the quality of care.

CONCLUSION

A strong sense of dignity is indispensable for maintaining quality of life, particularly among those who are most vulnerable and dependent on the care of others. It should be realized that while respectful treatment is one of the premises for dignity, it is insufficient in maintaining the care recipient's sense of personal dignity. It is suggested here that the understanding of personal dignity within the quality of life discourse could benefit from incorporating the findings and insights from research in the field of dignity studies. Quality of life instruments are often used to evaluate quality of care and for policy making. Because preserving the personal dignity in individuals dependent on care is considered a central aim of care, it is vital that dignity is measured in an adequate fashion. In certain situations it may be beneficial to assess the personal dignity of care recipients more fully by using purpose-built dignity instruments or by conducting face-to-face interviews.

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